Chapter 2

General Methods

The study had two over-arching objectives: to develop and test measures and indicators of quality of life (QOL) in nursing homes, and to study how physical environments affected QOL in nursing homes. In this chapter, we briefly describe our approach to each of these objectives.

Develop and Test Measures and Indicators

Research Tasks/Questions

To address this overarching objective, we articulated many separate tasks or questions:

1. Review literature and existing QOL measures, especially as they relate to frail older people.
2. Identify domains of QOL for residents of nursing homes.
3. Identify items to measure the QOL domains.
4. Develop reliable and valid measures of QOL.
5. Determine the extent to which QOL can be measured through direct interview with nursing-home residents, including with residents with cognitive impairments.
6. Determine how many residents need to be interviewed to develop stable estimates of average QOL in a facility.
7. Determine how facilities vary in their resident-reported QOL.
8. Determine how resident and facility factors affect QOL at the individual and facility level.
9. Test proxies for resident self-report, including responses of a resident=s direct staff caregivers or resident=s family member, and observation of resident affect.
10. Develop and test a facility-level observation tool as an additional proxy for resident QOL.
11. Identify possible indicators of QOL based on:

a. Existing data sets (MDS or OSCAR)
b. Data that could be collected from or reported by facilities.

Two Waves of Data Collection Strategy

We collected and analyzed data for this study in two large-scale waves, or phases. The first data collection was fielded in 2000 and the second in 2001. In between Waves 1 and Wave 2, we collected extensive pre-test data on the Wave 2 protocol. After both Waves of data were collected, we conducted a separate study in the Spring of 2001 to examine the transferability of both interview and observation data collection to facility personnel and surveyors. Table 2.1 compares the two waves of the study on some key parameters.

Wave 1. Wave 1 entailed data collection in 40 facilities in 5 states. We endeavored to draw a sample of 50 residents per facility. Wave 1 constituted the first major fielding of the QOL instruments. We included a larger number of putative items than we expected ultimately to retain; our intent was to shorten and refine the instruments as a result of this empirical test. We also included a large sample of residents with the intent of ultimately determining minimum sample sizes. The main foci of Wave 1 data collection as related to the measures and indicators were:

- psychometric work to develop QOL scales (scale consistency, reliability, concurrent validity, factor analysis)
- determination of the extent to which persons with cognitive impairment or serious physical illnesses can respond to QOL interviews
- testing of proxy approaches to resident QOL

Table 2.1. Comparison of Wave 1 and Wave 2

Parameter	**Wave 1**	**Wave 2**
Purposes	Field test measures for psychometric work. Determine who can respond by cognition. Test proxy informants on resident QOL. Develop extensive on-site programmatic data for possible indicator development. Collect data for environmental component of study. Proxy data collected on all residents, including those who could not be interviewed.	Confirm QOL measures. Examine resident correlates of QOL including personality and length of stay. Test shortened observational protocol.
States	CA, FL, MN, NJ, NY	CA, FL, MD, MN, NY
NH sample criteria	Stratified by size and rural/urban, and oversampled for 75%+ in private rooms. Entire state (MN, NJ) or substate (CA, NY, FL) catchment areas, the latter with at least 300 nursing homes. Volunteer NHs. Sample size 40 facilities.	Facilities enumerated in driving range of urban areas (Albany, NY; Baltimore, MD; Los Angeles, CA; Miami/Fort Lauderdale, FL; Minneapolis/St. Paul, MN); selected from top and bottom of a list arrayed by citation and staffing features thought to influence quality. Sample size 60 facilities.
Resident sample criteria	Facility census enumerated by unit, cognitive status from MDS, and single room status; sampled so as to select up to 20% in single rooms if possible, an even division between high and low cognitive functioning, and even representation of up to 10 residents from each nursing unit.	Resident census approached in random order.
Sample size	50 residents per facility (actually total sample was 1988 because several facilities had fewer than 50 eligible, consenting residents after exclusions. Approximately 1200 interviewees with QOL data; N varied by domain.	28 residents actually completing QOL questionnaires; total sample 1680.
Other data collected or used.	Staff interview for each resident. Family questionnaire when possible. Apparent-affect rating scale for 20% random sub-sample and all who could not be interviewed. Detailed programmatic data, staffing data, and environmental data at room, unit, and NF level. Facility level observational protocols. MDS data for sample and facility and OSCAR data for facility.	Streamlined facility level observational protocol. Administrator self-report questionnaire on facility programmatic data. MDS data for sample and OSCAR data for facility.

As part of Wave 1, also, we did extensive in-person data collection on facility programs and

policies that might affect QOL. In Wave 1 nursing homes, we interviewed (at a minimum) administrators, directors of nursing and social work and activity directors and collected detailed staffing information at the unit level. The intent was to use this experience to further refine the way to define and collect information on organization features affecting QOL and to use early analysis as a way to develop items for an administrator self-report in subsequent data collection.

Facility and resident sampling at Wave 1 was partly constrained by a need to over-represent homes with private rooms and residents in private rooms for the environmental part of the study. CMS requested that the sample be divided into urban and rural facilities and large and small facilities. Technically, we had a right to go into facilities as a research extension of the survey agency, but because Wave 1 entailed a heavy burden of data collection, only facilities that readily consented were chosen for the final sample. At the resident level, besides over-sampling for those in private rooms, we stratified the sample to include half with better and half with poorer cognitive functioning using an MDS-based measure.

In Wave 1, the final resident sample was 1988, and the number for whom we have QOL data ranged from 1,081 to 835 depending on the domain.

Interim Data Collection. As a result of Wave 1 data collection, we made slight modifications in the QOL questionnaires. In the interim before Wave 2 data collection was fielded, we extensively pretested additional items on individuality. We also developed and tested a self-report tool to measure personality. These tests were conducted with a purposive sample 200 residents in 6 nursing homes in 2 states.

Wave 2 data collection. Wave 2 data collection was conducted in 60 facilities in 5 states. The facilities were sampled on a random-stratified basis. To stratify the sample we used an algorithm based on positive and negative extremes on survey citation history and staffing levels.

Based on Wave 1 experience, we used a strict random sampling of residents rather than stratifying for cognition, and we continued to approach residents in random order until we obtained a sample of 28 completed interviews. (From Wave 1, we had learned that 28 residents would be more than sufficient to gather stable facility-level measures on all domains.) Wave 2 data collection was much more streamlined than in Wave 1. Our goals were as follows:

- Confirm the factors and properties of the QOL measures.
- Examine individual factors associated with QOL, including personality (not collected in Wave 1) and length of stay (with many more short-stay residents than the Wave 1 procedure allows. In Wave 2, we also had more racial variation in the sample to consider analytically because we chose geographically compact urban areas centered in cities with high African American and Hispanic populations.
- Examine facility-level factors associated with QOL in this more representative sample, using extant data and data supplied by each administrator.
- Test a shortened facility level observational protocol.

In Wave 2, the final sample consisted of 1,680 residents most of whom had completed all the elements needed to measure 11 domains.

Transferability study. In this separate study, the Wave 2 QOL measures and a somewhat modified observation protocol were tested in paired administration with research interviewers and a) facility personnel, and b) surveyors. The goal was to determine the extent to which the practitioners were congruent with research interviewers. The field experiment for facility personnel contained arms to modify the discipline of the staff assessors (nurse staff versus social work and activities staff) and the training intensity and format.

Environmental Study

Research Tasks/Questions

In the environmental component of the study, we asked the following general questions:

1. How do nursing home physical environments vary on factors that might influence QOL?
2. Can we identify subtypes of facilities based on environmental features?
3. How do physical environments affect resident QOL?
4. What is the relationship between being in a private or a shared room and QOL?
5. What innovative design features could be identified, and how did they affect QOL?

Data Collection

The study of physical environments required the development of new protocols for systematic data collection. Based on literature and expert opinion, we developed 3 observational checklists suitable for administration by a nonspecialist and largely without equipment for: rooms and baths; units; and overall facility. (Instruments and their development are discussed in Chapter 12, where environmental data are summarized). The room and bath protocols were administered during Wave 1 by the same data collectors who did the individual-level data collection, typically concurrently with administering the resident interview. The unit and facility protocols were completed by a single researcher (Lois Cutler) for the 40 facilities and for 131 nursing units.

After data from Wave 1 was collected and analyzed descriptively, innovative features were catalogued and selected for more intensive study using post-occupancy evaluation (POE) techniques. POEs entail detailed description of the features, systematic observation and behavior mapping, and interviews with those who use the environment (residents, visitors, staff, and volunteers).

Data reduction included creation of conceptually based composite scales to summarize and measure a variety of environmental attributes and cluster analyses to identify environmental

types. Recognizing that residents live in rooms that are nested in units that are nested in facilities, hierarchical analysis was planned.

Procedures: Wave 1

Below we provide considerable detail about sampling and procedures for Wave 1. Procedures for Wave 2 were similar, but sampling and data collection were less complex. Measures and analytic procedures are treated briefly but more fully described in the sections where the results are presented.

Selection of States

CMS requested that the QOL work proceed in five states. We recognized that 5 states would not represent the states in the country. Nonetheless, we aimed to strengthen the credibility of the study by selecting states that varied in the structure of their nursing home industry, their reimbursement rates and policies, their reported quality, and their labor force composition.

To select the five states, we gathered information on nursing homes in all states. For practical reasons regarding cost, we then excluded Alaska and Hawaii. To ensure an adequate sample of participating nursing homes, we eliminated an additional nine states with fewer than 100 nursing homes. Information collected from secondary sources for the remaining 39 states included: bed supply; ownership status; Medicaid reimbursement rates; deficiency data, both for quality of care and QOL; and percentage of population in the 65+ age bracket. In addition, special factors were identified such as state interest in participating, service milieu, labor force issues and innovative QI efforts at the state level. The list of states was narrowed down to twenty that represented a variety of current long-term care environments. These twenty were then arrayed on a grid to highlight the states that represented the high and low ends of each of

the parameters. In discussion with CMS, the list was winnowed down to 10 states and ultimately to the 5 that were chosen; each from a different CMS regional office. The 5 states ultimately chosen were: California, Florida, Minnesota, New Jersey and New York.

Because of the large number of facilities and the large geographic area for managing field work in California, Florida, and New York, we worked with state representatives to identify logical regions that comprised from 300-400 facilities. A multi-county area around San Francisco Bay comprised of four Survey and Certification areas was chosen in California. The central area of Florida was chosen, including the Tampa/St. Petersburg and the Orlando area. In New York, the western area comprising Buffalo, Syracuse, Rochester, and environs but excluding Westchester, New York City and Long Island, was chosen. The entire states of Minnesota and New Jersey were selected for the sampling frames.

Survey of Facilities in Catchment Areas

CMS had specified that the sample include large and small nursing homes in rural and urban areas. We also needed to over-sample facilities with a high proportion of private rooms. In addition, CMS was initially interested in including some nursing homes that were using satisfaction measures developed by the national nursing home trade association. Because information about single versus private room arrangements is unavailable in state data bases (Florida, which did require facilities to report information on types of rooms, was an exception) and quality assurance practices were definitely unavailable, a special survey was needed to get that information. We sent a brief mailed survey to all the nursing homes in the catchment areas. The intent of this survey was both to help us design the sampling process for facilities and also to illuminate facility activities related to QOL.

Accordingly, we developed a one-page survey protocol suitable for faxing (see Volume 2,

Appendix A). This was mailed or faxed to all facilities in the catchment area. It queried them about their physical facility design, their division into units, and their interest in and activities related to QOL. Also, because we were considering purposively including in the sample some facilities thought to have high QOL, we invited nominations and self-nominations for excellence in QOL.

We mailed 1744 questionnaires to the specified geographic areas in our 5 states, and had a 57% response rate (ranging from 77% response in Minnesota to 57% in California). The overall results relevant to sample selection are shown in Table 2.2. Facilities rarely had a high proportion of private rooms, though the rates varied by state. Also in many facilities, substantial proportions of the residents lived in rooms with 3 or more residents (not shown on the table). This reinforced the need for purposive sampling of facilities with private rooms. We also found that few facilities were using consumer feedback tools developed by the national nursing home trade associations, though most purported to be doing something to get systematic feedback from residents.

Table 2.2. QOL Facility Survey Results

	California N=143	Florida N=154	Minnesota N=336	New Jersey N=177	New York N=177
Surveys Returned	47%	49%	77%	49%	53%
Size Distribution:					
less than 49 beds	31%	19 %	16%	16%	11%
50 B105 beds	52%	33%	57%	23%	31%
106 + beds	17%	47%	28%	62%	58%
Median size	69.5	104	79	119	120
% Residents in Private Rooms					
More than 75%	0.60%	3.24%	2.98%	3.91%	5.02%
74%-50 %	1.39%	2.59%	5.37%	1.11%	4.46%
49%-25%	6.99%	6.49%	11.34%	3.91%	14.52%
Fewer than 25%	58.00%	72.02%	67.67%	86.00%	70.94%
None	32.96%`	15.58%	12.53%	5.02%	5.02%
Location:					
Rural	9%	43%	65%	11%	46%
Urban	91%	57%	35%	89%	54%
Information on units:					
Mean # of units	1.84 units	2.24 units	2.14 units	2.76 units	3.35 units
Had dementia unit(s)	11%	27%	33%	15%	24%
Had hospice unit(s)	5%	7%	6%	2%	2%
Had rehabilitation unit(s)	23%	45%	20%	45%	32%
Had other specialty unit(s)	15%	16%	12%	15%	11%
Consumer Feedback:					
AHCA or AASHA process	3%	8%	9%	19%	11%
Own Corporation	73%	71%	58%	49%	60%
Reported QOL initiatives					
Use of physical space	50%	66%	68%	71%	64%
New construction	15%	21%	48%	37%	29%
Equipment & appliances	61%	60%	71%	69%	63%
Renovations	50%	53%	67%	63%	63%
Furnishings	55%	58%	68%	68%	66%
Staff - scheduling and deployment	53%	68%	56%	58%	53%
Policies and procedures	64%	71%	57%	73%	62%
Philosophy	65%	68%	60%	69%	65%
Staff Roles	57%	68%	60%	69%	58%
Resident Programs	80%	81%	70%	86%	75%
Other	47%	53%	575	64%	58%

Selection of Facilities

We determined that we would select 7 of the 8 facilities needed per state in a random stratified manner, but that one (1) facility would be chosen as a perceived exemplar of a better-than-usual QOL. To select the exemplars in each state, we compiled a state-specific list of representatives from various organizations with statewide experience in nursing homes. In a telephone interview, we asked these respondents to nominate facilities that had made extraordinary strides in achieving a high QOL for its residents. The nominations were tallied and combined with nominations and self-nominations from the nursing home survey; nominated facilities were then rank-ordered in terms of number of nominations. The nursing home in each state with the highest number of recommendations was contacted and asked to participate. California respondents were unwilling to name facilities as exemplary, and we arbitrarily selected as the California exemplar a nursing home that had won a prize from the state survey agency the previous year for its work in individualizing residents and staff and that had a national reputation for its efforts to create a vibrant nursing-home community.

Except for the exemplar facilities, which in some cases did not respond to the initial survey, we used respondents to our QOL survey as the basis for selecting facilities. We realized that there would be an enormous field effort at each facility, and wanted to increase the chances of facility cooperation. We assumed that those facilities that returned the surveys were interested in QOL and, therefore, more willing to participate in the data collection process. Through the survey we also gained current information on private room status and occupancy, as well as information about any innovative design or systems that the respondent thought were in place.

In choosing the 8 facilities in any state, we needed to distribute them equally between urban/rural and large/small facilities. We also needed to include some facilities in each state

with high proportions of single rooms. We initially intended to include some facilities that utilized improvement tools developed either by the American Association of Homes and Services for Aging (AASHA) or the American Health Care Association (AHCA); our survey showed almost no use of those tools, and we dropped that sampling variable.

The facilities were first sorted into urban/rural, large/small categories using a system based on zip codes.[1] Facility size categories were determined based on the total response to our QOL survey. We established a minimum size of 50 beds for sample eligibility, thus eliminating 176 facilities. Facilities with 50 to 105 beds were deemed small and those with 106 or more beds were deemed large for the purpose of sampling.

Once the Aexemplar@ facility was identified and agreed to participate, it was placed in the appropriate category in terms of size and location. Facilities with a high proportion of private rooms (defined as 75% or more) were listed separately and randomly selected until two such facilities were selected for each state. These, too, were placed in their appropriate category in terms of size and location, and then random selection was used to fill out the rest of the urban/rural and large/small facilities grid.

Recruitment of Facilities

Eight (8) facilities in each state were selected initially using the process described. Each received a letter of invitation, followed by a phone call to the administrator. If the facilities were willing to learn more about the study and what their participation entailed, a recruitment visit

[1]National Resource and Policy Center on Rural Long-Term Care (1996). Guidebook for Operationalizing AoAs: Definition of Rural. Kansas City, KS. Under a grants from the Administration on Aging and the Kansas Geographic Bureau, separate guidebooks were created for all states, classifying each zip code as rural or urban. We used the guidebooks and accompanying CD=s for the states in the study to classify each nursing home as to its rural or urban status.

Those facilities declining such a visit were replaced by the next facility in that size and location category, and the same procedure was followed. This continued until all 40 facilities were recruited to participate in the study. Half of the randomly sampled facilities declined on the basis of a telephone discussion; typical reasons given were: staff shortages at the managerial or line level, new construction, recent or expected ownership changes, and distrust of the regulatory process. Forty-nine facilities (49) were visited in order to achieve the sample of 40 facilities. Replacements after a visit occurred because: the facility did not qualify; the facility decided not to be involved; or management changes made original planned involvement impossible. For example, the study group decided to replace one facility after a visit revealed that it was a state-wide referral center for residents with severe mental health problems.

During the initial recruitment visit, the study was described to the administrator, and often to key personnel with the intent that prospective facilities would be well briefed on the scale and scope of the study and their own roles. We structured the first wave of data collection with the participating facilities as partners in the effort, and this stance encouraged participation. Our Arecruitment packet@ consisted of the personalized letter of invitation, a letter from CMS that designated our work as a study related to the survey process, a brochure outlining the study questions, information about sampling within the facility, and versions of newsletter text that could be used to inform residents, staff and families about the upcoming study.

Facilities were excluded if they were: federal homes (e.g., VA Nursing Home Care Units), State Veterans Homes, MR-DD Facilities, Psychiatric Facilities, Hospital Swing Bed Units or hospital-based facilities with no clear demarcation between hospital and SNF, or specialized facilities serving younger residents. We also excluded facilities with fewer than 50 beds.

Selection of Units Within Nursing Homes

Because some nursing homes have considerable internal variation at the nursing unit level in terms of physical plant, staff, and case mix, it was recognized that a resident=s location on a particular nursing unit could influence his or her QOL. Also, this study required measuring physical environments, and again we needed to do this at the unit level if only to explore the extent of variation in environments within facilities. The decision on how many units to select required consideration of the minimum number of residents needed from a unit to examine QOL on that unit and the resource constraints governing the total sample who could be assessed for QOL in any facility and the number of environments that could be assessed. Given the developmental nature of this measurement effort, it was initially determined to include 50 residents per facility and we also determined that there should be no fewer than 10 residents from a unit. Therefore, we limited the number of nursing units to 5, and built selection of units into our overall sampling plan.

During the visit to each sampled facility, information about the units was updated and verified by the administrator or director of nursing. If the facility had a dementia unit (SCU), it was automatically included. Given that the mean number of units per facility was 3, in most instances; all the units in the facility were chosen. Only 5 facilities had more than 5 units, and in one of those the sixth unit was a small ventilator unit largely serving younger people. The project director reviewed those facilities that had more than five units, eliminating the most appropriate units. This was usually determined by the number of private rooms and cognition level of the residents, since the final resident sample needed to over-sample the former and be evenly divided on the latter. Table 2.3 shows the distribution of 131 nursing units in the study by state.

Table 2.3. Distribution of Nursing Homes in Sample by State and Number of Units

State	1 unit	2 units	3 units	4 units	5 units	Total
California	1	2	4	------	1	8
Florida	----	2	----	4	2	8
Minnesota	----	1	3	1	3	8
New Jersey	----	4	2	2	----	8
New York	-----	3	2	----	3	8
Total	1	12	11	7	9	40

Selection of Residents

The study design required that we measure the QOL for residents who have both high and low cognitive functioning levels. The decision was made to draw the sample based on the last recorded MDS for the resident. Even if not precisely accurate for each individual, we believed this would assure us a mixed sample and, moreover, would reflect how the resident was officially perceived by the facility. We used information on cognitive functioning from items in section B1, B2, and B4, ACognitive Patterns@ (Minimum Data Set 2.0). Those residents who were considered to be in a vegetative state (B1) were excluded from the sample entirely. Then, for all residents, we collected their scores for B2a, B2b, and B4, and summed them (Figure 2-1). Residents who scored 0, 1, or 2 were considered to be high cognitive functioning and those with scores of 3, 4, or 5 were considered low functioning for the purposes of sampling. The

instrument we used is similar to Morris et al.=s Cognitive Performance Scales[2] without the incorporation of items on functional ability such as the feeding items.

MDS 2.0 Section on Cognitive Patterns		**Score**
B1. Comatose	(Persistent vegetative state/no discernible consciousness.) 0. No ➔ calculate score as below. 1. Yes ➔ drop from sampling frame.	
B2a. Short-term memory	(Recall of what was learned or known.) B2a. Short-term memory OK—seems to recall after 5 minutes.. 0. Short-term memory OK. 1. Short-term memory problem	0 or 1
B2b. Long-term memory	B2b. Long-term memory OK—seems/appears to recall long past 0. Long-term memory OK. 1. Long-term memory problem.	0 or 1
B4. Cognitive skills for daily decision-making.	(Made decisions regarding tasks of daily life.) 0. Independent—decisions consistent/reasonable. 1. Modified independence—some difficulty in new situations only. 2. Moderately impaired—decisions poor, cues/supervision required. 3. Severely impaired—never/rarely made decisions.	0-3
Total score.		0-5

Figure 2.1: Cognition Measure Used for Sampling Residents

Residents were sampled so as to achieve the following results: 1) inclusion of at least 20% in private rooms when possible; 2) an evenly divided sample of those falling into the higher or lower cognitive functioning; and 3) an even division within units. We developed a sampling grid that we asked each facility to complete to provide information on all residents living on the units included in the study. Through this mechanism, we collected each resident=s name, date of birth, last four digits of their social security number, admission date, room number, number of residents occupying the room, most recent MDS assessment date, and data from the MDS on the items needed for us to calculate the cognitive scale. In those facilities that were unable to

[2]Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L.A. (1994). MDS cognitive performance scale, Journal of Gerontology: Medical Sciences, 49: M174-M182.

complete this data collection readily, a locally-based project interviewer did so. These sampling data were collected 2-3 weeks before the expected arrival of the QOL interviewers. Clearly, post-acute stay residents were, therefore, less likely to be available for the Wave 1 sample because they are often discharged within 20 days of admission.

We entered all sampling data into a database set up by units for each facility. An overall assessment was done for each facility, initially looking at private rooms on each unit and then at cognitive status. We then assigned a computer-generated random number to each resident. When completed, we used the sampling algorithm in Figure 2.2 to select the resident sample. As the figure illustrates, precedence was first given to selection of private rooms, then to assuring sufficient cognitively intact persons in the sample, and finally to the unit distribution. When the sample was drawn, we also drew replacements from the various units so that the Minnesota-based research group could instruct the field staff to make appropriate replacements for subjects who were deceased or had been discharged between the time we drew the sample and arrived at the nursing home. Residents were excluded from this process if they were: under age 65, comatose or in a vegetative state.

Tracking System

Members of the Survey Center at the University of Minnesota were involved early in the pre-tests and development of the data collection instruments. Their efforts helped with developing the response category formats, clarifying questions for content, and preparing the training manual.

#Private Room Selection

A. If #10 private rooms in the whole facility, include all. Once included,
T identify location of private rooms on perspective units
T identify resident=s cognition functioning (high or low), and keep count of each

B. If > 10 private rooms,
T identify location of private rooms on each unit

T select number of residents according to the following distribution:

# 2 units	5 residents	5 residents				
# 3 units	3 residents	3 residents	4 residents			
# 4 units	2 residents	3 residents	3 residents	2 residents		
#5 units	2 residents	2 residents	2 residents	2 residents	2 residents	

C. Compute number of residents remaining to achieve total of 25 residents with high cognitive functioning (MDS score 0-2).

D. Complete sample for residents with low cognitive functioning (MDS score 3-5) equally across units, if possible.

#If there is a Dementia Unit (SCU), include at least 10 residents from this unit

A. Select SCU residents using random number designation
T select at least ten residents

B. Other residents in rooms with two or more residents
T complete roster with high cognitive functioning residents
T then complete low cognitive functioning residents using SCU residents first.

#If there is no dementia unit, work at the unit level

A. Within each unit create a sample in the following order:
T Cognitively intact
T Other

B. Complete sampling across units as equally distributed as possible with number of residents for:

# 2 units	25 residents	25 residents				
# 3 units	17 residents	17 residents	16 residents			
# 4 units	12 residents	13 residents	13 residents	12 residents		
#5 units	10 residents	10 residents	10 residents	10 residents	10 residents	

#Replacements

T Each unit will have 5 replacements identified, if possible
T If not evenly distributed, sample to distribute as evenly across corresponding units as possible.
T As above check distribution of cognitive status and incorporate in the total count.
T Again, complete complement of cognitively intact residents across units as possible, then add cognitively impaired

TTrack reasons for replacement

Figure 2.2. Algorithm for selecting residents for the sample in each facility.

Because of the large and complicated field effort, with many multi-page instruments for each resident at multiple sites, it was important to set up a good tracking system. While pre-testing the different instruments, discussions of issues helped to establish the workflow, and the tracking system evolved as a result. Our system was set up to ensure that we could account for every instrument that left the office.

A tracking system was developed to ensure that instruments were assigned correctly to the specific resident in the correct nursing home. We developed a system of serializing all resident-specific forms. Each type of booklet was given a unique number, i.e. the resident interview was assigned 52, resident observation 53, and so on. Each booklet was serialized with consecutive numbers so that all pages had the same number. Each resident was assigned a specific serial number. We then created a packet of instruments for each resident, all pre-labeled and serialized, including a tracking form.

Logistics

While the instruments were being finalized, a massive field endeavor was planned. Because of the geographic location of the participating states, we approached the data collection in a step-wise fashion. We decided to roll-out the states in pairs, first Minnesota and Florida, then California, and finally New York and New Jersey. A time-line included training dates, and projected the start and completion dates of the facilities in each state. The training dates were: January 9-15, 2000 (Minnesota and Florida), March 5-11, 2000 (California), April 9-15, 2000 (New York and New Jersey).

The tasks to maintain the overall work flow included:

1. Finalizing recruitment of nursing homes in each state before training, including identifying the contact liaison in the facility and finalizing the selection of units.
2. Collecting names of all the residents on each unit with other demographic and MDS data.
3. Transferring the names to a facility database and specifying the resident sample.
4. Assigning a unique identifier for each resident and print labels.
5. Collating resident packets for each facility.
6. Preparing all other facility instruments which included facility-level observation for each interviewer, overall facility rating for each interviewer, and the reliability forms.
7. Double checking sample and all instruments against master list and boxing together by facility.

Once the instruments were completed for a facility, they were edited and data were entered. Receipt of forms from one facility triggered the release of forms for the next. The survey center monitored the progress of the interviewer, reviewed returned forms for completeness, sent family names to the QOL staff, and prepared instruments for key punch. Double-entry keying was utilized, data corrected, and the completed data file was sent to the QOL staff for analysis. The work schedule was staggered across the states, creating overlaps.

Over the same time period that we were developing the sample, preparing the instruments, and processing the collected data for one group of states, the next states= facility recruitments were being completed and the interviewers recruited and hired.

Hiring Interviewers

Two months prior to the first scheduled training in each area, ads were placed for research interviewers in local papers in the areas of the facilities in Florida and Minnesota. Our goal was to hire about 10 professional-level interviewers per state, preferably with experience in LTC.

The survey center director and her associate director assigned full-time to the project interviewed and hired 8 individuals from Minnesota and 10 from Florida. Later 10 interviewers were hired in California, and subsequently 8 for New Jersey and 9 for New York. Among the 45 interviewers were individuals with experience as administrators, nursing, social work, activities, psychology, education, research interviewing, and volunteers.

Training

Each of the three QOL training sessions lasted for 7 days. The research interviewers were flown into the Twin Cities on Saturday evening, and housed close to campus in a motel that also had a room for training. The training schedule consisted of the following topics presented in a classroom-type setting:

- Overview of the study
- Mode of conduct while at the nursing homes
- Informed Consent (This study was classified as an extension of the Survey Agency process and, therefore, did not require formal informed consent for us to speak to residents and review records. However, the interviewers needed practice in communicating about the study, and gaining the cooperation of the residents.)
- Interview Technique (This included material about how to probe without biasing, how to answer questions and work with difficult residents, and how to maintain a conversational tone while strictly adhering to the categories of the questionnaires.)
- Resident interview review and practice
- Video and training for the affect rating scale[3]
- Overview of room and bath observations
- Staff interview review and practice

[3]We used a video developed by Lawton, MP in 1998 called Recognizing and Responding to Emotion in Persons with Dementia, produced by the Philadelphia Geriatric Center and distributed by Terra Nova Films, 9848 S. Winchester Avenue, Chicago, IL 60643, 800-779-8491.

- Facility-wide observations
- Onsite work flow

After two days in the classroom with extensive role playing, the trainees were divided and sent to four local nursing homes where they practiced doing the resident interview, first with residents with higher cognitive functioning residents and then with residents with lower functioning residents, both under the direction of survey center staff. They also practiced their observation techniques, and had a special session with our environmental design specialist to learn the process of completing the Room and Bath assessment. After each onsite practice the group met with QOL and survey center staff to debrief and share questions, concerns and experiences.

The final full day of training consisted of testing and evaluation. All trainees were observed during interviews by staff of the survey center. Paired interviews and room and bath assessments were done to test inter-rater reliability. Paired observations of residents with QOL staff were also completed to ensure reliable observations. Any areas of weakness were noted. The last morning of training consisted of review of onsite procedure, communication, logistics, and first assignments.

To reinforce the training and assist with issues during implementation at the sampled facilities, staff from our survey center accompanied the interviewers during their first 3-5 days onsite in each state. The interviewers for any specific state were divided into two groups and assigned to one of the larger facilities. The survey center personnel helped them get organized and assisted in planning their work flow. In addition, the survey center personnel worked with

any of the interviewers who may have needed more help in one of the various data collection areas.

On-site Data Collection Procedures

Once the interviewers were onsite, several different steps needed to be completed to ensure a complete and efficient data collection effort. These steps included:

- Meeting with the site contact to exchange information about the facility tour and meet key staff on the facility units.
- Reviewing the sample list with the site contact and making replacements when necessary.
- Reviewing the onsite tracking grid and assigning residents to interviewers.
- Obtaining names of staff to assist them with getting family names, and then collecting the family information to send to University of Minnesota, from where the questionnaires were mailed.
- Identifying staff who have worked with sampled residents, obtaining their work schedules, and setting up appointments to complete staff interview.
- Seeking out residents to establish interview schedules and, when necessary, replacing residents according to the established protocol.
- Assigning interviewers to complete various reliability procedures (described below).
- Setting up schedules to assure that all meal and weekend observations are completed as required by protocol.

Interviewers were divided into two or three groups in a state and sent as a team into separate facilities. That way we had only two or three facilities in each state with active interviewing at any one time, and were able to be available for questions and follow-up. Interviewers alternated in the team leader role, which carried responsibility for coordinating communication with facility staff, assuring that all components of the protocols were complete, and sending materials back to the University of Minnesota. The survey center made a supervisor available at all times to answer any questions that arose in the field, and daily communication was planned between the

team leader at each site and the survey center.

Reliability Testing

After we established our procedures in the first facilities in the first two states, we introduced some formal testing of inter-interviewer reliability. These tests were conducted in 31 facilities.

Test-retest of Resident Interview. The purpose of this test was to determine whether the resident=s reports would remain stable over short time periods. In planning the test/retest reliability for the resident instrument, we were concerned that subjecting a resident to a second complete interview would be an unnecessary burden. In each of the 31 facilities where we performed these tests, 5 residents were selected and each was re-interviewed on 2 or 3 domains, the general questions on emotions, and summary items on QOL. To accomplish this, the interview tool was divided into 5 sections and in each facility a resident received a fifth of the domain items plus the general sections. To minimize interviewer variability, the same interviewer did the original interview and the re-test components[4].

Inter-Staff Reliability. In a different type of reliability testing, we explored how sensitive the staff interview might be to the idiosyncratic selection of a particular staff member. In each facility where this test was conducted, the team leader selected a second staff member to respond about 2 residents, one with higher and one with lower cognitive functioning. In each case, the second staff member selected had equal exposure to and chance to know the resident. The second staff member was not informed that his or her interview was for reliability purposes, and he or she received the same incentive and was interviewed under the same circumstances as

[4]Results in the test-retest proved difficult to interpret and the N reduced because of post-hoc rearrangements of items into scales. Therefore, we did a separate test-retest reliability with the finished instrument in three many level facilities at the end of Wave 2 Data collection.

respondents in the main data set. Again, the same interviewer conducted both interviews to minimize the effect of the interviewer style on the results.

Inter-observer reliability on room and bath protocol. To test the room and bath instrument, the interviewers doubled up on two room and bath environments, one shared and one private if possible. The team leader and one of the interviewers went together and completed the assessment independently but at the same time.

Inter-observer Reliability of Facility-Wide Observations. To test the facility observation instrument, the facility walk-through, one activity observation, and one meal observation were completed with two people doing it together and completing it independently. The facility walk-through was to be done independently of the other facility walk-throughs already assigned to individuals. For the activity and meal observations, a second observer simultaneously completed an independent rating.

The data collection effort at Wave 1 for all resident-specific data (resident interview, related staff interview, room and bath protocol, Apparent Affect Rating Scale, identification of family contacts for each resident), facility-level observation protocols, and all reliability testing at a facility required 2 to 3 weeks time for teams of 2 to 4 data collectors.

Environmental facility-wide assessments and on-site indicators

All the unit-level and facility-level observations were done by a single assessor with a doctorate in housing and design. This assured consistency in the observations, since the alternative of training 45 interviewers, each of whom would do few unit and facility observations was unacceptable. As a result of this effort, in addition to data on 1988 resident rooms and baths, we also have environmental data on 131 nursing units and 40 facilities.

In addition, the project director visited all 40 facilities to collect data on procedures,

policies, and staff deployment that might lead to proxy indicators of QOL. Briefly summarized here, the data collection effort included the following mixture of interview protocols and collection of quasi-archival material:

- Interview with the administrator or his/her designee.
- Interview with the director of nurses or his/her designee.
- Interview with the director of activities and/or his/her designee.
- Interview with the director of social work and/or his/her designee.
- Collection of detailed information about nurse staffing by day, shift, and level, both from payroll and registries, for each 4 specified one-week periods.
- Collection of activities records.
- Collection of admission materials and resident manuals.

As the study progressed, other materials were collected, including records from care planning conferences and lists of staff development materials. Also, depending on the facility and its programs, at times interviewers were conducted with additional types of personnel, including chaplains, staff developers, and dietary personnel**.**

Procedures, Wave 2

We continued with the states selected for Wave 1 with the exception that we used Maryland instead of New Jersey. This afforded us a state in easy distance of CMS, and an opportunity to sample a larger number of African American residents. We were also responsive to Maryland=s strong interest in participating in the study; at that time, Maryland was developing its own nursing home report card system and was interested in including a QOL component.

In contrast to Wave 1, (where we intended to select urban and rural facilities and stratified the sample accordingly) in Wave 2 we maximized field convenience by attempting to work within a 20 or if necessary 30 mile radius of a central zip code. We planned to begin with a

central zip code in a populous urban area and enumerate nursing homes surrounding that central zip code. We hoped to have a sampling frame of 100 nursing homes from which to select a target of 12 nursing homes per state. In Minnesota and Maryland, we built the sample around the two obvious large metropolitan areas: the Twin Cities (Minneapolis and St. Paul) and Baltimore, respectively. In California, Florida, and New York, we chose different areas of the state from the Wave 1 data collection. Specifically, we went to the Los Angeles area for California and the Miami/Fort Lauderdale area for Florida. We had planned to center the New York sample in Westchester County to incorporate a populous suburban area just outside of New York City. Because the New York data collection was planned to be phased in during October 2001, we changed our plans to respond to the disruption of the attack on the World Trade Center. We, therefore, drew the New York sample around the Albany area, ending up with a somewhat smaller pool of facilities from which to select than for other areas and a larger radius for travel.

Using OSCAR data, we arrayed the facilities in the catchment area in rank order using a score based on data on selected quality-of-life related deficiencies and staffing information. (As in Wave 1, we deleted facilities with fewer than 50 beds, psychiatric or MR/DD facilities, State Veterans Homes, and hospital swing bed units. We sampled facilities in rank order, seeking 6 working down from the top, and 6 working up from the bottom of this list. This procedure was meant to generate extremes on parameters that might possibly influence QOL.

We wrote to the facilities included in the sample, including a letter from CMS describing participation as mandatory. Six (6) facilities refused to participate without stronger directives from CMS, and ultimately we and CMS decided not to enforce that requirement and engender ill-will for the study: all refusals were in California and Florida, where recent litigation made nursing homes loath to be involved in studies. We deleted other facilities from the list because,

on further exploration, they were psychiatric facilities; they served largely young people, or had almost a complete non-English-speaking resident population. It was noteworthy that we dropped 8 facilities from the Los Angeles area based on the language criterion. The use of an inner city zip code as the fulcrum resulting in nursing homes where residents largely spoke Spanish, Korean, Vietnamese, Japanese, and Armenian. The excluded facilities were equally likely to have been drawn from the either the top or bottom of the sample list.

The census was sent to the research team a few days before the expected data collection in the facility, permitting us to array the sample in random order, and to note admission date with the census. Residents were approached in this random order and, as in Wave 1, comatose residents or residents under age 65 were excluded. Additionally, no resident was interviewed before he or she had been in the facility for at least 4 days. In Wave 2, we continued data collection until we had obtained 28 residents who were capable of completing an interview sufficiently for us to construct at least 9 of 11 QOL domain scores. This required approaching more residents in some facilities than others. Although facility personnel not uncommonly argued that we should skip them because they were certain that 28 residents capable of being interviewed could not be found, we declined to accept that prediction as a reason to drop a facility from the sample. As it turned out, we failed to obtain enough interviews in only one of the 60 facilities first sampled needed to be replaced because we failed to obtain enough interviews. Typically teams of 2-3 data collectors completed the resident interviews and observations in a facility within about a week=s time.

Training and field work quality procedures mirrored those of Wave 1 with one difference. We prepared the interview tool in a form that could be scanned and were able to determine in real-time and make corrections of missing data. This also eliminated the key punching step.

This chapter has summarized major methods used in Waves 1 and 2 of data collection. Information about many of the data collection tools themselves are reserved for the chapters where the results are presented. Similarly, the sampling approach and measurements for the special study of transferability to nursing home personnel and surveyors are presented in Chapter 11 along with those results. Appendix B through Appendix O in Volume 2 contain all the instruments fielded at Wave 1, including the following resident-level instruments: resident interview (Appendix B); staff interview about the resident (Appendix C); family interview about the resident (Appendix D); and resident affect rating scales, an approach we piloted but have not utilized in our analyses to date (Appendix E).